A Proposed Ontology For Online Healthcare Surveys

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ABSTRACT

This paper results from the research efforts of the Clinical Informatics Research Group in building a generalized system for online survey implementation. Key to the success of any generalized survey system is a standard ontology for the differing components of any survey, particularly those sought to be implemented online, over the World Wide Web. In this paper, we introduce the need for generalized survey authoring tools, discuss our methods for elucidating the different components present in many healthcare instruments and classifying them as per existing standards, and later present our proposed ontology for online surveys in the healthcare domain. Next is a more detailed description of the different question types mentioned in this ontology. Finally, we compare some general purpose authoring systems currently available to determine their flexibility in representing these disparate question types (www.cirg.washington.edu/SuML).

INTRODUCTION

Chronic Disease Management: Chronic Disease today accounts for huge morbidity and mortality. It is estimated that these diseases cause more than 1.7 million deaths a year, and lead to significant morbidity in 25 million individuals in the United States. The financial burden of chronic diseases accounts for 75% of the 1 trillion dollar U.S. healthcare expenditure.(1) Worldwide, WHO estimates that chronic disease will be the leading cause of mortality and morbidity by 2020, and will account for two-thirds of the global disease burden. The World Health Organization in its landmark report on "Innovative Care for chronic conditions" highlighted the need for a paradigm change in the health-care delivery mechanism.(2) Traditional healthcare systems are modeled on episodic, event-based care, geared toward acute conditions. Chronic conditions necessitate more continuity of care, with an emphasis upon the patients' role in their disease management.

Patient Data & Utilities in Chronic Disease: This continuity-of-care paradigm necessitates the collection of longitudinal data from patients. Patient assessment of their disease state is an important metric for determining the quality of care being rendered. Availability of patient assessments to care givers and planners could contribute toward cheaper and more effective healthcare. (3) A number of self-administered healthcare instruments have been developed to measure patient symptoms as well as their utilities and are also helpful in comparing patient outcomes across institutions and time periods, thus helping in understanding disease trends. Although it is important that physicians and caregivers have access to this data at all times, physical resource limitations have always proved a huge stumbling block.

The Internet in Chronic Disease Management: A necessary and cost-effective method of both patient data collection and targeted patient education is through applications delivered over the Internet. Earlier studies have commented upon the lack of patient access to the Internet, but current estimates are heartening. The U.S. Census estimates that 54 million households (51% of the entire population) have computers, and an estimated 94 million people use the Internet at home. (5) This paves the way for using the World Wide Web (web) as a convenient portal for disseminating patient educational materials, as well as collecting patient data from a majority of patients in the U.S. and other developed countries.

General Purpose Survey Authoring Systems: A wide variety of approaches have been used to implement healthcare instruments online, ranging from simple HTML forms to more complex programs incorporating multimedia objects. Several projects have successfully used the Internet both to collect patient data through the use of HTML form based surveys, as well as deliver tailored information based on the responses to the questionnaires. However all these programs have tended to be developed for a single survey, and are not readily adaptable to other questionnaires or domains without considerable recoding. This leads to increased costs, thereby decreasing the cost-efficiency of the wide access of the Internet. Furthermore, the response data is stored in an inaccessible format, thus making comparisons across surveys and integrating this valuable patient data into clinical patient record systems a big challenge, threatening the continuity-of-care approach. Generalized Survey Authoring systems help overcome many of these challenges, by providing easy to use survey authoring tools, which can create a broad variety of surveys without coding

and minimal expertise, yet provide a standard data model for response data integration. These systems can also incorporate powerful logic patterns thus allowing for the use of complex skip patterns, branching in surveys, and customization of questions following previous responses (piping). The essential pre-requisite to developing a robust survey authoring system is a comprehensive ontological description of the survey, including the survey components, its question types, and the variables being studied. The next few sections describe one such model for surveys.

METHODS

A general schema for healthcare surveys was created, broadly based on the specifications laid out by the Triple-S consortium, the industry standard in market research and other social science surveys.(6) We then sought to classify a representative set of healthcare instruments based on this schema, and refine the ontology based on these results. We selected survey instruments that are routinely used to measure Quality of Care, and certain disease-specific measures used in the evaluation of chronic lung diseases in adults. We identified validated, widely used Quality of Life instruments from the published literature, as well as those with which our colloborators within the UW schools were familiar.(7) We used paper versions of the surveys when available, otherwise using versions represented by the Medical Algorithms Project.(8) In addition to these instruments, we also referred to our implementation of AsthmaNet. It is a symptom-based questionnaire for children with asthma built with the SuML (Survey Markup Language) system, which was developed by the Clinical Informatics Research Group. (9) (17).

The principal author (SH) then manually extracted and classified the question types and other characteristics of these instruments. These were then discussed between the academic advisers, and consensus was reached on the classification method.

The sheer number of these instruments makes scrutinizing each of them almost impossible. The QoLID project lists 350 quality of life instruments, and there are many more disease-specific measures, as well as several under development. (10) We have therefore tried to elicit a broad variety of question types from the instruments studied to ensure the robustness of our ontology.

SURVEY STRUCTURE

Surveys can be thought of as being comprised of three components:

Content: This portion describes the various questions contained in a survey and the possible answer options which accompany the questions. It also contains meta-data about the authors, title, intended audience, date of authoring, etc. This kind of meta-data is important when third party tools are used to merge the data generated from these surveys into a standard format such as the Data Documentation Initiative (DDI) format.

Display: Questions, while having the same format, could be laid out differently either on screen or on paper. There has been considerable research on changes in response patterns attributable to differing formats. Hence the display of the questions remains a key issue, and each of these components is more fully described in the sessions below.

Logic: Logic within a survey refers to several different entities, which are described more fully later. Briefly, the routing that is followed in a survey, the actions to be taken based on responses to previous questions, and the scoring of certain responses or the summation of responses can all be thought to comprise the logical components of a survey.

SURVEY CONTENT

The major bulk of the survey content has to do with the questions that are asked in the survey. We identified several different question types, and have tried to reconcile them by comparing them with established authorities in the field of survey methodology. (11)

Questions can be thought of as having a leading content, which is the text of the question, an answer that may contain several variables, and variables may be of several types.

The survey literature classifies question types as:

Comment Questions: These are questions with no answers, but are meant to guide respondents through the survey. This is the form which educational material being presented after surveys would adopt. Since there are no answers, it doesn't contain any variables.

Open-Ended Questions: These are questions that do not have preset answer choices. Participants are free to enter their response without any constraints. The significant downside to this approach is the inability to elicit accurate answers, so open-ended questions are not favored in most surveys, and we did not find many in our sample of healthcare indicators. However, these are indispensable when collecting specific demographic data like names, addresses, etc. These could have two variable types, numeric or character types.

Close-Ended Questions: These are questions that have a certain number of preset choices, constraining respondents to restrict their answers to one or more of

the choices provided. It is here that we find the widest variety of variable types. These are best described in the survey literature as: (12)

Nominal Variables: Those responses that do not have any intrinsic order to them, such as racial identifiers, etc. While most of these are single response items, we did identify some multi-response questions in our sample as well.

Ordinal Variables: These are the most commonly used variable in our healthcare indicator sample. Ordinal variables permit some ranking/ordering of the study population, but the exact interval between the different responses cannot be ascertained. These were primarily represented in our sample as Likert type questions.

Interval Variables: These levels of measurement assume that the intervals between the different answer options are of equal lengths. The visual analogue scale to represent health state in the EuroQOL Quality of Life questionnaire best illustrates this type. Measurements of temperature and blood pressure are also classic examples of this sub-type.

SURVEY DISPLAY

There has been far more agreement on variable types than on the display or formatting of questions. This does not preclude the importance of formatting, since published studies have shown considerable difference in response patterns based on the screen layout of questionnaires. There are several different methods commonly used for displaying answer choices:

Radio- buttons: Usually adopted for single response items in keeping with the HTML specifications.

Check boxes: Used for multi-response items, also in keeping with the HTML specifications.

Drop down lists: These are used for single response items, especially where a long list of options exists, such as the State where a person lives. Rarely, they are also used for multi-response items.

Two-column display: The usual method of representing answer options is in a single column format, but where there are an increased number of options, designers sometimes opt to use a two-column format to prevent the need for excessive scrolling on the part of respondents.

Categorical Grids: These are used extensively in our healthcare indicator sample. Similar ordinal variables are grouped together as may be seen in the Medical Outcomes Study physical dimensions of health.

Image Maps: These are images sometimes used to represent both interval scales, such as the intensity of pain measured by marking a point on a straight line, as well as nominal responses, such as the location of pain marked on a human figure.

Ordered Responses: Answer choices are represented in some form of order. Most of the surveys that we studied presented their choices in this format. But situations exist where a random order may be necessary to eliminate bias, and a system must be able to generate options in a random order.

Single screen vs multiple screens: Questions may be displayed either on a single screen for each question, or having multiple questions on a single screen. Some innovative studies have demonstrated different response rates

SURVEY LOGIC

The logic components of surveys cover a broad spectrum. It is helpful to classify them based on their role in the survey, using algorithmic & flow pattern concepts.

Navigational: These relate to the order of questions asked. Most simple surveys place skip patterns following a negative response. These are usually represented in online systems as simple GOTO statements. More sophisticated surveys have many complicated, branching patterns following a single response or based on a set of responses. Yet another type of navigational logic is the use of either pre-conditional logic, which lists a series of conditions which must be satisfied before a certain question is asked, or post-conditional logic which has a list of conditional statements which must be executed immediately after the question. These conditional statements may be simple ASK commands referring to following questions, or could involve other forms of scoring logic.

Response Coding & Validation: Coding refers to the process of assigning numeric codes for text responses, to enable easier statistical analysis and manipulation. Validation, on the other hand, enables restriction of the user to a certain data type or data range in open-ended questions.

Data analysis logic: While sophisticated analysis is obtained by importing the response data into statistical systems, some surveys require the ability to generate simpler analysis of response data on the fly. Common analysis methods include *Indexing,* which refers to simple summation of the codes used for all the variables in the survey. *Scaling,* on the other hand, refers to the summation of only questions related to a specific topic or only those of a certain

variable type. Both these may sometimes assign a differential *weighting* to each variable. We believe that all these are components of a survey and not

	Content					Display				Logic				
Instrument Name	Open Ended	Nominal Variables	Ordinal Variables	Interval Variables	2 column display	Categorical Grids	Ordered choices	Image Maps	Branching	Skip Logic	Response Coding	Scaling (subscores)	Weighting	Indexing
Medical Outcomes Study & other QoL Measures														
Short Form-36 (SF-36) Health Survey		✓	✓			✓	✓				✓	✓	✓	✓
Short Form-20 (SF-20) Health Survey		✓	✓			✓	✓				✓	✓	✓	✓
Short Form-12 (SF-12) Health Survey		✓	✓			✓	✓				✓	✓	✓	✓
Short Form 6 Item General Health Survey		✓	✓			✓	✓				✓	✓	✓	✓
EuroQoL 5 item survey			✓				✓	✓			✓	✓	✓	✓
Social Support Index														
The Duke-UNC Functional Social Support Questionnaire			✓			✓		✓			✓			✓
The 27-item social support questionnaire of Saranson	✓		✓				✓				✓	✓		✓
Comorbidity Index and Score of Charlson et al	✓	✓	✓			✓	✓				✓	✓	✓	✓
Lung Disease Measures														
Chronic Disease Score of Von Korff et al Using Drug Data	✓	✓	✓			✓			✓		✓	✓	✓	✓
McMaster Asthma Quality of Life Questionnaire		✓	✓			✓	✓				✓	✓	✓	✓
Asthma Quality of Life Questionnaire (AQLQ) - Jeniper		✓				✓					✓	✓	✓	✓
Chronic Lung Disease Severity Index		✓	✓			✓					✓	✓		✓
St. George's Respiratory Questionnaire (SGRQ)		✓	✓	✓		✓					✓		✓	✓
Quality of Well Being (QWB) - Robert Kaplan		✓	✓			✓			✓		✓	✓	✓	✓
AsthmaNet Symptom Based system	✓	✓	✓	✓	✓				✓	✓	✓	✓		✓

TABLE 1: Survey Components of different healthcare indicators.

externalities, hence survey authoring systems should be able to model these to fit the diverse needs of healthcare surveys.

RESULTS

Table 1 describes the survey characteristics of several different healthcare instruments, based on the ontology that we have developed. As is apparent from the figure, most of our sample set of instruments had questions with ordinal & nominal data types. Some of them did include open-ended data types, but these were a minority in our chosen set.

Most of the ordinal question types were presented in a categorical grid format, where the response choices remained the same for different measures. Most of these choices were arranged in an ordered format. Some measures such as the EuroQoL used image maps to indicate the site of pain, while the UNC support questionnaire used a 'measuring stick' image to enable respondents to indicate their choice.

The greatest unanimity amongst all these indicators seemed to be in the type of data analysis required. All of these measures had their responses coded, either into numerical codes or values that were then factored into the final scales or sub scores. Most measures reported sub scores from selected questions, which appeared either close to each other or were scattered throughout the survey. Finally, some responses were weighted in the final analysis. One of the most complicated surveys that we studied was AsthmaNet that was modeled on the NHLBI guidelines, and thus reflected the complexity of guidelines, which involve significant branching and skip logic. Further, this was the only survey that contained educational material at the end of the survey based on the responses generated. (9)

DISCUSSION

It can thus be ascertained that Generalized Survey Authoring systems must be able to handle this wide variety of question & variable types, formatting requirements and logical and analytic requirements. It should be kept in mind that this ontology does not list all the possible question types and other survey characteristics. It is rather, an initial attempt to develop a working formalism for developing robust survey authoring systems, and also generate a methodology for evaluating the plethora of systems currently available in the marketplace today.

We studied four such contemporary survey authoring systems to determine their capabilities, and have attempted to catalogue their capabilities in Table 2 below. This does not purport to be a formal evaluation of these systems, but is meant to illustrate the dearth of systems that are robust enough to handle the needs mentioned in the preceding paragraphs. Individual characteristics were obtained from the

product descriptions & specifications on the individual websites. We hope to conduct a more thorough evaluation as this work continues.

These systems represent the wide variety of systems currently available. Catalyst WebQ is a homegrown system developed by the Educational Technology Development Group at the University of Washington, Seattle (13). SPSS MrInterview is a commercially available system that is web-based, from SPSS Corporation. (14) Survey Solutions is developed by Perseus Development Corporation and allows surveys to be created in a word-processor like interface. (15) WebSurveyor is also a web based survey solution marketed by WebSurveyor Corporation. (16)

As can be seen from the table, no system in our small sample comprehensively meets the requirements of our ontology. Further all these systems utilize inaccessible methods of survey representation, and this limits the possibility of integrating this data with clinical information systems. Therefore the standardization of a data model for survey representation is imperative in order to facilitate the routine collection and use of patient entered data in the management of chronic diseases. It is hoped that continuing research in this domain of survey computing would result in the specification of such data exchange standards, and this proposed ontology may help in both the development of robust Generalized Survey Authoring Systems and facilitate their interaction with clinical systems through interchange standards.

Survey Features	Catalyst WebQ	SPSS MrInterview	Perseus	Web Surveyor
Open Ended	✓	✓	✓	✓
Nominal Variables	✓	✓	✓	✓
Ordinal Variables	✓	✓	✓	✓
Interval Variables	✓	✓	✓	✓
2 column display		✓	✓	
Categorical Grids	✓	✓	✓	✓
Ordered choices		✓	✓	
Image Maps				
Branching			✓	
Skip Logic			✓	✓
Response Coding		✓	✓	✓
Scaling (subscores)				
Weighting				
Indexing	✓	✓	✓	✓
Data Validation	✓		✓	✓

TABLE 2: Capabilities of selected survey systems

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http://www.cirg.washington.edu/SuML

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